

CO13-002–EN

Regulator aspects concerning limitations on care

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CO13-003–EN

Ethical issues concerning the Leonetti law and its application for people with severe brain damage

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Keywords: Legal aspects; Withholding and withdrawing medical treatment; Severe brain injury

The French law of 22 April 2005 on patients' rights and end of life has two main aims: the strengthening of patients' rights and the recognition of specific rights for end of life. This law prevents two risks: aggressive treatment and euthanasia. *Objective of the study.*— To examine the issues raised by the application of this law to patients with severe brain injury hospitalized in intensive care and rehabilitation units.

Materials and methods.— Analysis of the legislation, of the French medical deontological code (art. 37) and of current recommendations of the "Société de réanimation de langue française" (SRLF).

Results

— for ICU, the SRLF recommendations also iterate the precise definitions of the commonly used concepts: medical treatment and care, unreasonable treatment, palliative care, withholding and withdrawing of life support in ICU. Collegiality and traceability are strongly recommended;

—during rehabilitation, the situation is quite different, the patient is not dying as long as basic care is provided (including providing water and food orally or through a gastric tube). The purpose of support is functional and the concept of "quality of life" is strongly associated with "project of life".

Discussion.— The procedures in ICUs and rehabilitation units are different even though patients are not always able to express their will. The practice of advance directives in France is not widespread.

In rehabilitation units it would be useful to have professional recommendations, as has been done in intensive care, to guide physicians faced with these delicate questions.

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Respite/rehabilitation hospital stays for rare neurological diseases and severe disabilities: Reporting on the experience 2003–2011

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Keywords: Modernization of care; Creation of a network; Improvement of the quality of life of the families involved

The respite/rehabilitation program was launched in 2003 when a new accessible and automated wing was opened with the aim of progressively expanding the capacity to 30 beds by 2010. In 8 years, we have been able to serve approximately 1000 neurological patients. Those patients, who normally live at home, stay with us for an average duration of one month.

They are generally referred to us by centers specializing in rare diseases such as they exist in the Paris area (AP–HP) or in other major cities, and by partner

physicians working in the field of physical handicap in places such as Garches or La Pitié.

The stays are designed according to a collaboration charter, which defines the objectives specific to each pathology. In collaboration with the various Patients Associations we have established a questionnaire, which targets each specific disease and its rehabilitation needs. This questionnaire is completed before admission and allows us to greet the patient being fully aware of his/her needs and equipped to meet them.

Our specialty.— Summer stays designed for patients from various backgrounds (students, people in the work force. . .) who can benefit from our "handiplage" site, a beach specially equipped to offer outdoors activities to individuals with physical disabilities.

We also have a special unit of 8 beds to care for patients with spinal injuries hooked up to a ventilator, once they become stable after surgery. One of the 8 beds is marked for a patient eligible for respite/rehab care.

This department also offers a myology consultation, which is open to both patients staying at the hospital and outsiders.

The hospital is set up to offer accommodations to visiting families and 8 studio apartments are available to relatives who wish to stay near their loved ones.

Overall the experience has been extremely successful and the social impact of such a program, which combines support for the caretakers and rehab, should be emphasized.

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Self-assessed well-being in a cohort of chronic locked-in syndrome patients

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Keywords: Locked-in syndrome; Quality of life; Survey; Coma; Consciousness; End of life

Objectives.— Locked-in syndrome (LIS) consists of anarthria and quadriplegia while consciousness is preserved. Classically, vertical eye movements or blinking allow coded communication. Given appropriate medical care, patients can survive for decades. We studied the self-reported quality of life in chronic LIS patients.

Design.— Hundred and sixty-eight LIS members of the French Association for LIS were invited to answer a mail questionnaire on medical history, current status and end-of-life issues. They self-assessed their global subjective well-being with the anamnestic comparative self-assessment (ACSA) scale, whose +5 and –5 anchors were their memories of the best period in their life before LIS and their worst period ever, respectively.

Results.— Ninety-one patients (54%) responded and 26 were excluded because of missing data on quality of life. Forty-seven patients professed happiness (median ACSA +3) and 18 unhappiness (median ACSA –4). Variables associated with unhappiness included anxiety and dissatisfaction with mobility in the community, recreational activities and recovery of speech production. A longer time in LIS was correlated with happiness. Fifty-eight percent declared they did not wish to be resuscitated in case of cardiac arrest and 7% expressed a wish for euthanasia.

Conclusions.— Our data stress the need for extra palliative efforts directed at mobility and recreational activities in LIS and the importance of psychological or drug therapy. Recently affected LIS patients who wish to die should be assured that there is a high chance they will regain a happy meaningful life. End-of-life decisions, including euthanasia, should not be avoided, but a moratorium to allow a steady state to be reached should be proposed.

Further reading

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